Stigma and the Ethnographic Study of HIV: Problems and Prospects

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This article reviews the factors of sexual culture formation and stigma in the representation and prevention of HIV transmission. Two views of stigma, insider versus outsider meanings and practices, are contrasted in the history of anthropology and sexuality studies. Changes in ethnography and the understanding of ethnographic method since the rise of the AIDS epidemic are considered through a series of case studies. The implications of this work for HIV education and interventions surrounding stigma management and community action are summarized. The author advocates the study of stigma as a means to enhance education and prevention efforts in cross-cultural research on AIDS.

KEY WORDS: ethnography; AIDS/HIV; stigma; sexual culture.

INTRODUCTION

Do local people understand the nature of stigma differently than the outsider? How does sexual stigma affect the whole person and citizenship? In the past, ethnography was primarily for description; now, ethnographies of HIV are trained on the study of resistance to stigma, disruption of prejudice, and change in sexual cultures and the production of new prevention practices or policy networks that challenge stigma. This lens on HIV stigma and the effects of stigmatization upon persons with AIDS or those accused or suspected of being HIV positive is useful in taking stock of the growing conviction, now prominent in medical anthropology and social medicine, that social inequality breeds disease and should be the true object of social analysis by all who are concerned with ameliorating the human condition in the new century.

If we conceptualize the epidemic as a process of disease and illness across time and space, and imagine those places in which AIDS has had the most impact, then we begin to understand how discrimination, stigma, and the tenuous structures of civil society have influenced rates of HIV infectivity, whether by color, gender, sexual orientation, etc. People in these vulnerable populations do not hold the same ability or have at their disposal the same resources to protect themselves—certainly not protection from a disease such as HIV (Diaz, 1998). These issues cluster around the central idea that social inequality harms health in civil society; as diverse sexualities and sexual cultures confront stigma and discrimination, processes of resistance, marginalization, social mobilization, and their challenges precipitate sexual diversity and the mobilization of sexual cultures within contemporary civil society (Herdt, 1997; Long, 1997; Weeks and Holland, 1996).

What role does the local “sexual culture” (a set of symbolic meanings and practices that regulate sexual conduct) and “social community” (a collectivity of people in face to face relations) play in these processes? The stigma of sexual cultures holds a key to understanding this issue. In this article I examine the role of stigma in ethnography and HIV study, highlighting the contrast between how sexual stigma is hidden from outsiders and how it is acted upon by local actors. Moreover, the possibility of being restigmatized or, better yet, “superstigmatized” by virtue of how HIV/AIDS amplifies the discredit that is heaped on the marginal group. Time and again in the history
of the epidemic, the vulnerable were stigmatized by virtue of their marginality, first Haitians as a social community, then homosexuals as a sexual culture, followed by commercial sex workers and bisexuals, who were blamed or later “restigmatized” through the accusation of AIDS. In each of these cases the outcome depended in part on social injustice and the ability of a community or sexual culture to defend itself, mobilize public opinion, and challenge the deepening effects of stigma (Farmer, 1999; Herdt, 1995; Levine, 1997).

Anthropologists worry a great deal about their data, criticizing and examining field material, and the fit between theory and social reality. For if it is true, as a demographer once remarked, that anthropologists find “meanings” while epidemiologists find “facts,” ethnography faces a never-ending struggle of charting the changing contours and meanings of sexual cultures and communities as they unfold or fission across historical time. One or two generations ago it was regarded as taboo to change a culture actively. “Observe, but do not change the culture,” Malinowski (1953) warned in Argonauts of the Western Pacific. Gradually, “action anthropology” began to advocate for social change to ameliorate situations of underdevelopment and colonial oppression, but not without many controversies. Throughout this period of accommodation to the realities of the postcolonial world, anthropology did not fundamentally alter its view of sexuality (Vance, 1991) or its taboo on sexual interaction with local people (argued by Herdt, 1999). For two generations, with occasional exceptions (Ruth Benedict’s work is critical here), anthropologists maintained this policy and deepened their commitment to nonintervention as a result of the Vietnam War (Di Leonardo, 1998).

Then along came AIDS in the early 1980s. While a variety of trends has hastened the transformation of anthropology, most importantly the effect of postcolonialism, none of these have influenced the study of sexuality and sexual culture as has HIV/AIDS. The AIDS epidemic challenged ethnographers to become involved, rather than remain aloof, and transposed the issues of sexual interaction with the “natives” of a local sexual culture into the context of the fieldworker’s own society (Herdt and Lindenbaum, 1992). While a growing number of colleagues have criticized anthropology for moving too little or too slowly, that is, in failing actively to promote behavioral change or to change cultures to stop the spread of infection, AIDS, in this sense, has unwittingly liberated ethnography from the bygone ideology of before, but it has introduced grave new problems of theory and method. Of particular importance here is the stigma of sexual orientation or role and discrimination against sexual minority cultures (gays and lesbians, bisexuals, and transgenders, as well as sex workers). As anthropologist Weston (1993) has written, “Lesbian/gay studies in anthropology is no longer easily separable into the product of ethnographer and natives, or even ethnographers who double as informants.”

This intellectual change and resistance to it are understandable effects of anthropology’s historical commitment to cultural relativism—an epistemology that sanctifies the coherence of cultures and the context of cultural practices above all. However, the taboo on sexual interaction between field-worker and local people noted above also derived from the sense in which anthropology’s aim was first to describe, and only secondarily to explain, the norm; the deviant, marginal, and stigmatized were largely excluded from the purview of study [with the exception of such examples as the “untouchables” and Hijras of India (Nanda, 1990)]. Thus, the marginal, aberrant, or exceptional were of import in understanding the maintenance of positive social control, but they were largely ignored as a problem to explain or an area of study in anthropology (Edgerton, 1985), especially sexual minorities [see, for example, the critique of Mead’s 1935 study, where marginals were regarded as biological deviants (see Herdt, 1991; Di Leonardo, 1998)]. Of course, culture change, the study of individuals, and, occasionally, the study of stigma entered into cultural accounts, as can be seen in the famous work of Ruth Benedict (1934) and others. However, in general, stigma was left to the sociologists, those scribes and muckrakers of our own society, and it was not until nearly two generations later that they got around to studying sexual minorities and stigma (Gagnon and Simon, 1973). While anthropology examined the whole person and his/her culture, sociology shed light on the social margin and partial society, especially the conflict and integration of incomplete citizens into nations. Personhood and citizenship are relative constructs, of course, but for the purposes of this paper we may define personhood (with Mauz) to be the full set of rights and duties bestowed upon the person by category criteria, such as beliefs and social status, conventioned by the community. By citizenship is meant a member of a state who is enfranchised to vote and enjoy the privileges thereof (Weeks, 1985; Weeks and Holland, 1996). With regard to the ethnography of HIV and stigma, what is increasingly important in the most sophisticated anthropological studies today